

*Nora Rothschild*

# COMMUNICATING TOGETHER

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AS ABILITIES CHANGE

COMMUNICATING TOGETHER VOL. 17 NO. 1/SPRING 2000



Theme for this Issue: The Right to Dream



## The Right to Dream Because .....

SHIRLEY McNAUGHTON

As many of our longtime readers know, the themes for each issue of **Communicating Together** are decided upon at our annual meeting of Associate Editors. This year, because it is our last year of publishing, a spring meeting was not held. We had already decided upon the format and themes for our final three issues (beginning with the next issue of **Communicating Together** Summer, 2000). This meant that as we began our work on this current issue, our discussion back in April, 1999 regarding its theme had faded from memory. Several of our associate editors began to question, "Just what *were* we thinking of when we arrived at this topic?" It had followed so naturally within our group discussion that we had not taken notes. We now had to think hard about where it had come from! Here's what I remember!

We were deep into expressing our concerns regarding the current reduction of services and opportunities for those with disabilities in Ontario, when one of our associate editors interjected, "Their dreams are being taken away!" We began citing examples in housing, education, transportation, social opportunities, attendant care, recreation, and even computer functionality — no new construction of subsidized housing, the reduction of special and adult education funding, fewer accessible transportation vehicles, prohibitive restrictions being placed on travel to social events, poorly trained attendants, fewer recreational programs open to persons with special needs, the increasingly rapid technology changes rendering three or four-year-old

computers inadequate for specialized internet use, and lack of volunteers to train persons with disabilities to use computers. The trend toward reduced services and public interest was perceived as extinguishing hope, and with it, the stuff of which dreams are made. Someone said, "AAC users have the right to dream!" That's how I remember it!

Those of us who were AAC users or who worked with AAC users in the seventies know all about dreaming! We dreamed of full and rich communication through powerful graphics blending with the newly developing personal computer technology. We dreamed of people moving into the communities in which their families lived and leaving behind forever the huge institutions in which many AAC users had been placed in the fifties and sixties. We dreamed of greater educational and vocational opportunities for all those who lacked functional speech. We even dreamed of our Bliss users having computer communication over distance, as the eighties approached! At the time, many would have thought we were fantasizing, but the many positive changes we were witnessing made it possible for us to dream!

And we actually saw many of our dreams being realized. New housing, new educational programs, a few job opportunities here and there, inclusionary recreational programs — they were becoming a reality for a growing number of persons with disabilities.

But with the coming of difficult financial times in the eighties, attitudinal changes toward services for persons with disabilities changed. New terminology began creeping into our vocabulary — efficiency, cost-effectiveness, pragmatism, hours of care

*required*, critical mass — as justification for a service, etc. In Ontario, service agencies were being forced to cut back on their programs and government services were having their funding reduced. Programs began to be judged on a different rating scale and *quality of life* became a phrase to be avoided when applying for funding. A business paradigm was permeating health, education and social services. Those whose needs could appear excessive and not compatible with the designated criteria could easily be overlooked in the delivery of services. Results that could be measured in a short period of time were sought. Persons with severe disabilities for whom progress was of necessity very gradual were often excluded. With the change in attitudes and resources, it became increasingly difficult for many persons with disabilities to dream of better days. The trend, for them, seemed to be heading in the opposite direction.

### Dreaming

Dictionaries offer several variations to the meaning of the word dream. It can represent "a series of thoughts or images passing through the mind in sleep", "a fancy or vision more or less freely entertained while awake", or "a cherished or vain hope or ambition". In this issue of **Communicating Together**, we are referring to a blending of the latter meaning along with what is described in the dictionary as the informal meaning, "something so perfect, wonderful, etc. that it can hardly be accepted as real". When we think of the right to dream, we refer to a hope or ambition that is perceived by us to be so wonderful that its realization can hardly be accepted as possible. Nonetheless, it is a cherished ideal from which we gain pleasure in the envisioning! In order to



dream, one needs to be able to hope that positive changes are possible, even if remotely so. Does not everyone have this right?

In the AAC field, much attention is given to communication as critical to our essence as human beings. To communication, I would add dreaming as another important ingredient of our humanity. My own dreams have been carefully recorded and kept in a file folder that is readily available for browsing whenever it might appear that reality is reducing my ability to dream. When I look back over the dreams and reflect on which ones have been realized, and which ones have not, I regain hope. For even those dreams that have not been fulfilled have brought wonderful friendships and exciting learning. Often a new direction has been taken because of a dream and this has led to undreamed of possibilities. One comes to realize that it is not the dream always coming true that is most important, but that one continues to dream! For this indicates that one has hope for better days. I agree with Nola Millin that dreaming is likely important to our mental health. In fact, I would suggest it would be a valuable measure of our mental health. Being able to dream tells us much about an individual's mental wellbeing. I am always disheartened when I meet someone who no longer dreams! And I would hazard that when one lives one's dream, as Paul Marshall describes, one's mental health is very good indeed.

What do I notice about persons who dream and who maintain hope for better times in the future? They seem, first, to have a pride in their own identity reinforced with a strong belief system, and second, they have a nurturing and enabling environment. It seems to be this combination of an individual's strength accompanied by a supportive environment that sets the

stage for dreaming. And the sharing of dreams with other dreamers can set in motion a chain reaction that will lead to the formation and realization of new dreams!

### **By Their Dreams They Shall Be Known**

I love learning about people's dreams! After all, many of the day-to-day activities in which people are involved are dictated by their life circumstances. We may not learn much about an individual, especially someone with a disability, by merely observing his or her daily routines. But their dreams! These reveal their deepest aspirations and desires. Whenever I visit Greg Gittings (see feature article, pp. 4-6), I know he will share with me a little more of his dreams for AAC users, for organizations like Cubs and Scouts and the Olympics to be truly inclusive, and for AAC users' homes to provide growing/learning environments. I know he will inquire as to whether I see his dreams having a greater chance of being realized than when last I visited. He knows the importance of others joining him in his dreams, for them to become a reality. I am delighted he agreed to write about his dreams for **Communicating Together** readers.

As several of the articles in this issue demonstrate, dreams come at many different levels. They range from Nola Millin's dream of completing her article, to her being able to travel from one city to another without worrying about whether the transportation systems, hotels, restaurants, and entertainment facilities will be accessible. Or from Geb Verburg's dream regarding the environment (shared by many of us) of the world's people taking care of "that precious and limited resource which our children and grandchildren and we need to survive", to the dream that he and others will have a job next year.

Suzanne Clancy's article illustrates another aspect of dreaming. Her dream for a useful education program for adults with all sorts of disabilities would seem to have been fulfilled, only to recognize that it will require her constant nurturing to continue. Peter Lindsay talks about the possibility of technology helping fulfill a major dream of most of us — the dream of a richer, more satisfying social life.

My dreams exist at all levels those relating to a positive outcome for a particular meeting I will be attending, to rich learning opportunities for family members, to improved life situations for AAC users, to a quality of life worth living for all persons within my city, province, country, world. The sharing with others and an involvement in organizations allow me to work toward at least partial realization of many of my dreams. For me, this includes working toward an Ontarians with Disabilities Act within my city and province, belonging to the Council of Canadians to support national dreams, and being committed to the goals of Blissymbolics Communication International (BCI) and ISAAC to help realize international dreams for persons who use AAC. I feel fortunate to have the time, health and energy to work toward my dreams. And I derive great joy in enabling others to work toward and sometimes realize their dreams. This issue of **Communicating Together** is providing a forum for our associate editors to share their dreams. By doing so, I hope we have succeeded in drawing attention to the right of every individual to a life situation that makes dreaming possible. When we see AAC users deprived of this right, I hope we take action.

I wish you the desire to dream and the realization of some of your dreams. I also wish you success in enabling others to dream!



### GREG GITTINGS with MAUREEN O'KEEFE



Greg Gittings

*We are delighted to include this impressive example of what results from an AAC user exercising his right to dream. The following article provides yet another example of what can be produced through the collaborative effort of a dedicated volunteer working with an AAC user with many literacy challenges.*

*Maureen O'Keefe has been tutoring Greg for the past three years as part of her ongoing commitment to The Oakville Literacy Council in Oakville, Ontario. Prior to this, Maureen worked with physically involved young people for most of her 25-year career in special education. She began volunteering when, in 1992, she moved to Canada from the United States. During her many years of teaching persons with many types of disabilities, Maureen discovered that "Even with greater sophistication (of technology), the emotional content*

*of conversations was difficult to express and understand. Being given the means does not always provide the tools to relay the depth and intensity of feelings."*

*Before reading what Greg has to say, consider Maureen's description of their collaborative process.*

#### From Maureen O'Keefe

**I**n producing this article, Greg used a Macintosh computer with Write Outloud software, (Don Johnston Inc.) for his written communication and his Bliss book (Bliss-symbols from Blissymbolics Communication International) for his face-to-face communication. He did not use full sentences for me to transcribe, so we set about finding the procedures that would help us move through the process most efficiently. Initially, Greg started out trying to write his thoughts. Without much background information, I was having some difficulty getting the whole concept from him. Therefore, I asked him to write single words that would give us a place to begin. This he did. I would then ask questions stimulated by the word he had written. We began to formulate a very broad picture of what was on his mind.

However, he had not developed any details around the ideas up to that point. It was summer and we took a bit of a break. His job over that month or so was to do a lot of thinking about his dreams, to

focus on what it was he wanted to say to people who had no idea who he was or what was on his mind. He also was to continue to develop a vocabulary list of words associated with his ideas.

When we picked up our sessions after a short break, we worked to bring more detail into his thinking. I would ask questions that I thought a stranger might ask. When told, for example, "I would like to get the world aware of what we can do." I would ask "How will you do this?" "What can you do?" "Why is this important to you?" We used Greg's Bliss communication system as well as the computer, where Greg would try to express himself. Many times Greg's spelling was inadequate to convey words that I could interpret. Then we would go to the Bliss book or I would continue asking questions until I found a lead. I would often print Greg's text and we would talk it through while I would write on my copy spelling corrections and other words to create complete sentences. Then we would talk some more about each sentence to be sure that I had captured first the factual content and then the opinion or feelings Greg wanted to add.

We began writing drafts of little pieces of text, then attempted to connect them. Greg worked very hard at all of this since he was forced not only to organize his thoughts, but to convey them to me





*Greg working at his computer.*

through writing. Writing and spelling skills are not an area of strength for Greg, but determination and patience certainly are. I used our literacy work as a reference to Greg's expressive skills. I also feel that I have come to understand somewhat Greg's value system, the things that he prizes and some of the things he imagines, from the time I have spent with him over the past three years. We have shared a lot about life events and our feelings which I expect has assisted us in this collaboration.

I hope I have done justice to Greg's need to express his dreams. It is important for him to be heard and equally important for others to hear!

*We thank both Greg and Maureen for putting so much thought and time into sharing Greg's dreams with our readers. Some samples of Greg's original writing has been interspersed in the text in capitals.*

#### **From Greg Gittings**

**M**y name is Greg. I have cerebral palsy. I am 35-years-old and have my own apartment. I am an augmentative and alternative communication (AAC) user. I have big goals and dreams.

A very meaningful event, for me, happened in the 1940s. Mr. C. Bliss made up a new system for communicating which did not require verbalizing. Mr. Bliss used visual symbols to create his system in the hopes that people worldwide would be able to learn the system and be able to communicate with each other. He believed that a common language would lead to better understanding among people of different countries and would promote world peace. In 1972, five children in Toronto who had cerebral palsy needed a way to communicate and wanted to follow this method. They were introduced to Blissymbolics at the Ontario

Crippled Children's center, now called Bloorview-MacMillan Centre. They wanted to be heard, but sadly they were not and still today they are not being heard. They were friends of mine. Sometime later I joined them and also was trained in Blissymbolics at Bloorview.

Along with other AAC users I would like to get the world aware of what we can do. I would like to be part of the 2014 Olympics and march in the opening ceremonies with other AAC users and physically challenged persons. I would like to plan a skit that will demonstrate that AAC users are intelligent, can think, have ideas and can communicate. I would like to show the world that we can be part of the community and help the community to be better.

Our skit would be designed to show the typical responses of people who do not understand anything about alternative methods of communicating. We would show an AAC user, with a Bliss



board/book or an electronic language device or a head pointer with a language board, etc. approaching someone on the street to ask for directions or some other type of help. Then we would role-play the different types of responses the speaking person might give to the AAC user. These might include the person looking at the AAC user strangely and walking away, the person not making eye contact and walking away, the person simply ignoring the AAC user as if he were invisible, the person stating that he/she does not have time for games.

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SOCIETY IS NOT AWARE BECAUSE  
SOCIETY DOES NOT MAKE TIME  
TO HEAR US.

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The second part would demonstrate a productive exchange between a person on the street and an AAC user. For example, a role-play would be used to show a person asking, "Are you OK?" or "How can I help you?" or taking the time to ask how s/he can communicate with the AAC user. In this way people will learn that we can communicate and we can have conversations with them. We would try to express the feelings that both the verbal and non-verbal persons were feeling while trying to communicate, feelings such as: anger, sadness, anxiety, fear and confusion. In addition to the role-play we would use visual arts and creative lighting.

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I HAVE BIG AND GOOD GOALS  
TO

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I would like to ask the Cub Scout organization to find Cub Scouts to be our legs and march with us. We would ask them to

help us plan our skit by doing the artwork and helping us move through the skit. I would like to show that Cub Scouts and AAC users can work together on one big project. When I was younger the Cub Scout organization was very important to me. I had a very positive experience in the Cub Scouts. It was a happy time. People assisted me and helped me feel that I could participate. I think this project would be fun to do together and I think it is something I can do. At the end of the skit we would have a big display of lights to show enlightenment saying, "I GET IT!", along with fireworks.

It would be wonderful to have access to living areas in the Olympic Village that would promote independence. I wish I could

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CUBS AND CAA USER CAN WORK  
TOGETHER ON ONE BIG PROJECT

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design a section of the Olympic village for AAC users. This idea connects to my dream of designing a permanent home for AAC users. My plan would be to build a log structure with apartments intended for independent living. I chose a log structure because I like the way it looks. These apartments would be designed to maximize independence for the physically involved resident. It would be a plan that included bigger doors, bathrooms with facilities that are more easily accessed (e.g., pool baths), an electronic communication system that would allow more hands free communicating about daily activities through television, telephone and computers, a central network computer system that would deliver classes or workshops for mathematics, reading, communicating, job skills and other life skills.

Workshops could be planned for both AAC users and personal attendants. An area I am particularly interested in is nutrition. I am not able to shop and prepare my own meals. I would like to see workshops given for attendants to help them recognize good nutritional choices when they shop and plan for meals. It would be good for them to have information on how to cook and prepare foods in a more healthy way. This would be a great help towards cooperative planning for better nutrition between physically challenged persons and their personal attendants.

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MY DREAM IS TO DESIGN AN  
APARTMENT FOR AAC USERS

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All of these services and activities would be available in one place. It would be a total community environment planned to increase independent skills. For me, it could possibly open opportunities to be able to work. I would call it a Learning/Living Centre. If this building became a reality I would like to name it after Tracy Roberts. She was the first manager of the Oakville March of Dimes building. She was inspirational to everybody and left a great void with her untimely death.

My dream of a home, whether it is realized or not, is a memorial to Tracy Roberts, Charles Bliss and my first Cub Scout leader, who was a good man, the kind of man I hope all young boys could meet.

My greatest dream is to find ways to help society make time to hear AAC users and understand that we are intelligent people, that we are people who have a lot to offer a community and that we can talk to you.



## Missing Steven Hanlon

ALDA STEPRANS



*Alda Steprans*

Steven Hanlon passed away Easter weekend and I'm still having a hard time accepting this. I did know that he was going to die soon. It was obvious that he was getting weaker and weaker. Yet, I so strongly feel his presence each time I go near the hospital he lived in, each time I visit someone in the community who has Huntington's disease or someone who has difficulties communicating. Each time I speak to one of these people I remember what Steven taught me: Take time! Have patience! I have something I want to say! Try to understand me! Laugh with me! Cry with me! Understand my frustrations! Share my joy!

Steven was indeed a remarkable fellow. He felt and lived life fully. He adored his wife Kim. On every visit I made, he would show me what Kim had brought him, told me how hard Kim was working. Her visits made his day, and when she couldn't come, just the memory of her would make him very happy. He was very proud of his loving family, his many brothers and sisters, nieces and nephews. He was always excited to share his album with their photos. He loved the art work his nieces and nephews sent him. He often talked of his and Kim's parents. His respect for them was very apparent when he told stories of his past. Humour, food (especially that nice cold beer), sports and games were his other great loves in life. He could watch Star Trek, cartoons, comedy shows on TV for hours, but whenever I came to see him the TV was off in a flash and Steve was ready to talk, talk, talk.

Over time, as is typical of people who have Huntington's Disease, being understood became increasingly difficult for Steven. In a way, I was even happy to have to tell him that **Communicating Together** would no longer be, because Steven always wanted to write another article and it was becoming so hard to understand him. Sometimes after an hour's work, I had only understood one or two sentences. If I didn't understand Steven, he made it clear and persevered until I had it right! The

joy on his face when I finally understood made me keep on going back. I sure had a weak spot for that smile of his!

Steven lived in a hospital and had many caregivers that he was very fond of. I'm always amazed at the wonderful people who work in this setting, especially the ones who take that little extra time and effort to joke a little, do something special for the people they care for. I've learned a lot from them as well!

Steven was especially fond of Lois, a hospital employee in the Activities Department whose sense of humour uncannily meshed with his own. Those two could spend hours joking around. He simply thrived on good humour and weekends, without Lois, were always a little glum for Steven.

Of course, Steven's story could not be complete without mention of Audrey McGee, who also writes for **Communicating Together**. Although Audrey is a little older than Steven, these two formed a special friendship in the hospital. Both had difficulties communicating verbally, but it was apparent that they communicated in other ways. They spent many hours playing games together, especially dominoes, and always watched out for each other. I get the sense that for Audrey, like for myself, Steven hasn't really died yet. He may not be there in person, but he seems to be around. His presence is still very strong.



When Steven was dying, I was lucky to have the chance to thank him for all the wonderful things he taught me. I couldn't name them then and I can't name them now, but perhaps in time I will be able to put those feelings, those notions into words. I just know that when-

ever I meet someone who has difficulties talking, Steven's presence is there with me: Take the time! Be patient! Don't be afraid! Keep trying to understand!

**Communicating Together** also gave Steven something very special. It gave him a forum to express himself to the world. What an amazing gift for someone who had so much difficulty being understood!

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**"Each time I speak to one of these people I remember what Steven taught me: Take time! Have patience! I have something I want to say! Try to understand me! Laugh with me! Cry with me! Understand my frustrations! Share my joy!"**

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## **AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION**

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### The Dream Builder

*This poem by Carol Lynn Katsios was written as a tribute in 1989 upon the retirement of Shirley McNaughton – now shared by her with all those who "linger" where their presence can matter!*

The Dream-builder passed  
by the sea-shore one day,  
By the side of the sea  
where the small things play;  
And her heart was drawn  
to those not so strong,  
To the ones that seemed lonely,  
who did not belong.

She carried the dreams  
on her soft golden wings  
Of countless ages  
of men and Kings,  
To implant in men's hearts,  
and fancy their minds,  
So that castles could rise  
on the sands of time.

But the small ones she loved  
had no voices to raise,  
And their hands could not build  
in the sun-lit days.  
Yet she knew that their dreams  
could all be full-filled;  
She could teach them to sing,  
she would teach them to build.

So she gave them her voice,  
and she gave them her hands,  
And she built them great castles  
in the golden sands;  
And she stayed by their side  
'til they grew firm and strong,  
And she watched them with pride  
as they learned their own song.

Now their hands build their own dreams  
as they push back the night,  
Now their voices soar with the splendour  
of eagles in flight;  
As the Dream-builder ponders  
the castles that grow,  
She knows in her heart  
it is time now to go.

When the Dream-builder passes,  
she will leave once again  
A new era dawned  
in the hearts of all men;  
And tomorrow's castles  
will rise shimmering and strong,  
Because the Dream-builder lingered  
by the shore with her song.

**Carol Lynn Katsios**

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## The Right to Dream

GEB VERBURG

*We are very pleased to have Geb's contribution to the dreaming theme. As usual he takes a very broad sweep at the issues. But his sweep is thought provoking.*

The new Millennium, what better reason for dreaming, hopeful, precious, optimistic, utopian dreams. Dreams that may inspire us. Dreams that will make our Millennium. If we had a say: What would we want these millennium dreams to be?

A woman on Mars? (We did the man on the moon thing already). Enough food for everyone of earth's inhabitants (this is an old dream that we still haven't made good). Could we dream for an end to unhappiness, an end to loneliness, a more humane and a more democratic world? Does anyone dream of a clean (as in unpolluted) earth? Do we dare to dream of a society in which power, greed, and self-gratification are no longer the driving forces behind most of our frantic activities?

Or do I need to be more realistic and pray instead for a square foot of space, a handful of rice and a cup of potable water a day for every earthling by the middle of the new Millennium? If, of course, there is still any inhabitable earth left by then and earthlings to inhabit it. I think I will settle for what I think are manageable dreams and small fervours. I will dare to dream with Christopher Reeve that the newest discoveries in nerve regeneration research will actually allow him and others like him to walk and run and ride a horse again.

I will also dream with too many workers that they, you and I will have a job next year and maybe the year after? I will also continue to dream that we will break the 40% employment level for people with disabilities in this millennium. I am quietly optimistic about that. After all, the unhealthy or almost insane urge of business to continue its year over year growth requires more and more consumers. And a consumer without a hefty paycheck is not a consumer. So whether we want it or not our children will be forced to attain more education (so they can work in the new jobs that require more education) and we will have to work more, and probably longer, so that they can earn more as we spend more.

An even scarier picture is painted by a Canadian investment advisor (Gordon Pape) who wrote a book based on the premise that

we will all live much longer than our parents. This leaves us with two options. Either we retire much too early for our, or any government's, retirement funds to last us for life. Or else, we will be forced to work till we are seventy or over. I'm certainly not enthused by these particular future scenarios.

I will continue *not* to dream with the businessmen and businesswomen that next quarter's profits will be larger than this quarter's and that in the best of their worlds this will continue to be so, ad infinitum. Because I believe that the unlimited growth and unchecked globalization of business (e-commerce or other) is unholy, unhealthy, and seriously damaging to our planet and our humanity. Not just because small is more beautiful but because small is identifiable, small is family, small is community, small can be next door, or in your city, or town. Small is not the multinational company that is spread out over seven continents, spans seven seas, employs the equivalent of the populace of a small nation, and has more wealth than the GNP of several mid-size nations.

I am very optimistic that someone will finally bring out the "CP-accent modifying chip". This chip which will in its early versions be installed in telephone-like devices that take the characteristic speech of a person with cerebral palsy (CP) and modify it so that it sounds like regular language. I hope that, even though the princi-



ples for this work may come from the field of rehabilitation research and development, the development and commercialization will actually be done by the movie industry. This industry could have a serious interest in its development and miniaturization. Such a chip would be ideal for an actor or actress who plays the role of a person with CP to actually use his or her own voice and just modify it to have a more or less severe CP-accent. (Assuming that the process of modifying voice can work either way). Even more of a benefit would derive from actually having more movies with realistic characters with disabilities playing roles (or cast in such roles) in the movies. Persons with disabilities are still a very under-represented segment of the population in the entertainment world. This calls for another dream). Major movies with people who have or portray disabilities in leading and popular and significant roles.

Attitude is still a big problem, one that requires a very special dream. This one comes compliments of my friend Audrey King. We were commiserating the fact that it is so difficult to get people to understand disability issues and to feel comfortable with disabled persons unless they have been there themselves. Audrey thinks that it would require nothing less than a short-term global paralysis of everyone (or of the most intractable types) before we will become aware of the problems faced by people with disabilities. Imagine everybody immobilized except the bona fide disabled. In the meantime we keep hoping that every time a significant event happens (a *Man in Motion*-like event, or a Christopher Reeves event) we

hope for a little while that disability will become a political agenda item. That this event will put disability issues on the map forever. It does not, and may not ever.

However, the new World Health Organization's international classification of functioning and disability (<http://www.who.int/icidh>) (ICIDH2) is being beta-tested. The definition of disability is (hopefully forever) specified in terms of societal participation, as well as in terms of activities and body systems. The inclusion of social participation in the definition is a major accomplishment and something that needs to be made required reading for everyone, at least for every university student who intends to work with people with disabilities. Too many of these students still come to practical situations with too little knowledge of real disability issues.

I will continue to dream with the ecologists that we will finally begin to take care of that precious and limited resource on which our children, grandchildren, and we need to survive. I see too little evidence of this coming true in my own city. Recycling continues but garbage pick-up is increased from once to twice a week. People continue to litter and waste, and green spaces are being turned into roads or buildings at an alarming rate. Do our children realize that trees clean the air and cities don't?

I want to stop my dreaming with some of the questions that *Popular Science* addressed in its January 2000 issue. To wit: "Will humans survive to the next Millennium?" Apparently 86 percent of people now living

believe so. I'm not at all sure. "Can we stop aging?" In many ways I hope not. I dread the thought of 6 billion plus people living even 20 years longer. "Will we clone a human?" I guess that this has been done already, in secret, somewhere. When I think of the miracles that genome research will bring I can only be silent. I do not dare to think of what is possible there.

I was also asked to talk about becoming independent. Here I do not need to dream at all. One of the writers of *Communicating Together* has started to write a column in his hometown newspaper. Great going Paul! The best of luck and may the readership of the *Hamilton Spectator* increase every year. There are more and more ways in which people with disabilities can voice their opinions and can become independent and in becoming independent let people around them learn about their abilities. Adolph Ratzke has a website (<http://www.independentliving.org/>) with a regular 'news and events around the world' column and an opinion section where people can vent or argue their views (reminded me of Nola's *Yuks and Wows* column). And then there are ways in which researchers are finding new and innovative ways of trying to listen. An example is the Childhood Disability Research Discussion Forum (sorry about the long name) at <http://www-fhs.mcmaster.ca/canchild/opportunities.html>. Here people are asked to present what they consider to be the real issues that need to be investigated in the new Millennium. I hope to meet you there.

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# REFLECTIONS

## Dreaming

NOLA MILLIN



*Nola Millin*

When I think about dreams, I tend to put them into two categories; the attainable and the highly unlikely or the fantasies. I'm not saying that all dreams can't come true but in reality there are some dreams that are highly unlikely to come true. I mean it would be nice if a gorgeous, single, muscular, wealthy — make that extremely wealthy — man would come knocking on my door, sweep me up in his arms, and we'd live "happily ever after!" That is certainly a dream but, let's face it, the chances of that happening are slim.

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**"I want to be able to travel from one city to another without worrying about whether the transportation systems, hotels, restaurants, and entertainment facilities are accessible. I want to live in a province where a person with a disability has equality"**

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The attainable dreams are just that — they are attainable. Obviously, by the time you read **Communicating Together**, my dream of a completed article will be a reality. Just because it's attainable doesn't necessarily make it less of a dream. (My other dream is to be able to spell without relying on spell checker (It just let me know I spelled "necessarily" incorrectly). For me, the ability to dream about attainable things is important. It helps me reach my goal and/or to plan ahead. I guess I'm a very goal-orientated person and I'm also very organized so if I dream about a finished product, a desired posses-

sion, or an upcoming event, it gives me the drive I need to get to where I want to be. In this case it's as simple as producing a written article. Actually, when I have my article done, I won't have to worry about receiving e-mails from Peter and/or Shirley asking me where my article is!

Other dreams are attainable but they may take a while to become reality. I have a perfect example of this. I've always been a cat lover (and dog lover) but they didn't let us have pets where I live because the attendant care staff doesn't have time to care for them, which I understand. Well, they're changing policies and are now saying that as long as persons can take care of the pet by themselves, with very minimal help from staff, then we can have pets. (I just took a few minutes to play with Patches, a white six-month-old kitten that has black patches and a black tail.) My dream of having a cat became reality three months ago!

I think people with disabilities have dreams like other people (my gorgeous hunk is out there somewhere!) but we also have dreams about issues that are related to our disabilities. I recently addressed the Liberal M.P.P. who is responsible for disability issues. I was encouraging the government to establish a strong and effective Ontarians with Disabilities Act. In my presentation, I stated some of my dreams for this province. I said that I want to be able to travel from one city to another without

**A**s I sit here staring at a blank computer screen and a blinking cursor, I am dreaming of having a completed article for this issue of **Communicating Together**. We are dealing with the theme of *dreaming*. Everyone has the right to dream. In some cases, dreaming helps people get through the day. Dreaming takes away the loneliness, gives people hope, and gives people a way to escape reality.



worrying about whether the transportation systems, hotels, restaurants, and entertainment facilities are accessible. I want to live in a province where a person with a disability has equality, a province where an individual has access to decent housing, to public transportation, to public facilities, to information, and to getting meaningful employment, regardless of their disability or medical condition. I really believe that this statement may become reality one day but for now it's a dream.

I dream about individuals with disabilities having choices of where they live. Accessible housing is limited and supportive housing, which is housing with attendant care staff, is even more limited. I know that in Windsor there are only a few options of supportive housing. The other concern is that they're all run by the same agency. The bottom line is, if you have a problem with the policies of the particular agency, you don't have any other options except a nursing home or rest home facility. Yes, there are in-home care programs but, again, if a person needs an accessible apartment or house or if a person needs more care than the in-home service provides, the person is denied a choice. Even if a person wants to move to a different location in the city, they're limited by the lack of accessible housing. So, one of my dreams is to see more choice in housing.

The same goes for attendant care. There needs to be more attendant care with flexibility in their policies. I would like to see cities and provinces set up a data

base so a person could travel from one city to another and be able to get attendant care services in the city they are visiting. In one way, this dream can be a reality with direct funding. I don't know that much about direct funding, but, from my understanding, individuals handle their own disability allowance and hence have the responsibility for hiring and firing their own attendant care staff. This would certainly give persons more freedom and flexibility in that they could take their attendant care staff wherever they wanted to go. For those of us who don't have direct funding, it's my dream that there would be more flexibility within agencies that provide attendant care services — that agencies will one day be willing to service visitors for the duration of a visit. I know this would be helpful for me. I have many friends who live throughout Ontario but for one reason or another they can't do my physical care. It would be nice if I could get care in the city that I'm visiting. It's often difficult to find friends to go places with me.

Another dream of mine is to have faster service delivery of products that people with disabilities need to use. I have been waiting for an assessment for a new wheelchair for over a year. People can go out and buy a car, or a house, or whatever faster than I can get an assessment for a wheelchair. It's pretty sad. I hear a lot of complaints about how long it takes to get an AAC device. So I dream of a better way to get equipment in a hurry.

These are only some of my dreams. The important thing is that

I have dreams and I'm allowed to dream them. I certainly don't live my life dreaming, or daydreaming, but it's nice to let my imagination go wild for a while and think about what could happen. You wouldn't want to know the number of times I have become an attendant caring for an actual staff person, in my dreams. Sometimes my dreams help me to cope with life. When dreams are attainable, they allow me to stay focused on what I'm doing. Dreams that are more like fantasies allow me to think of a better life. I don't have any statistics but I would bet dreams are very important to our mental health.

By the way, if you see my gorgeous man you had better warn him that he has to be a cat lover because Patches is definitely going to be a part of my life for a long time!

I hope some of your dreams come true!

§



## Still Dreaming After All These Years

SUZANNE CLANCY

For the last twenty-four years, I have been a community college professor, specializing in employment readiness for disadvantaged adults. From 1975-79, I worked with high school dropouts, single mothers, alienated youth, and ex-offenders, providing vocational assessment, academic upgrading, life skills instruction, and job readiness training in a government sponsored program. In 1979 I accepted a handicapped adult into my program, only to discover, to my dismay, that he did not qualify for training because he received a permanent disability pension and was therefore, by definition, unemployable. Fortunately, we were able to secure private funding for this student who subsequently completed the program and secured full-time, competitive employment in the community.

Having come face-to-face with government policies which seemed at the very least short sighted and, at worst, discriminatory, I began to dream of a full-time community college job readiness program designed specifically for handicapped adults. Such a program should enhance their independence, build self-esteem and demonstrate that

handicapped adults had the desire and ability to work in the community if given appropriate education and training, and reasonable accommodation in the work site.

### A dream come true

My dream became reality in the fall of 1980 in the form of our school's THAT Program. For the last 20 years I have devoted much of my energy to administering, and teaching in this program for scores of handicapped adults at Mohawk College in Hamilton, Ontario, Canada.

With funding from the provincial and federal government and much support from Mohawk, I have been privileged to teach a wide range of developmentally and physically handicapped adults, including those who were nonverbal and others with multiple handicaps. My mandate included the provision that successful completion of the program would be measured by whether the students achieved their work goals. Some desired competitive employment, while others were more comfortable going into to a sheltered setting before seeking work in the community. A third group devoted their time and energies to the volunteer sector and often expressed great satisfaction and pride in being able to earn their pension by making a contribution in our community rather than just sitting at home.

To his immense credit, it was Paul Marshall, a long-time contributor to **Communicating Together**, and one of my founding students, who fostered the notion of volunteering as a way of "repaying" his community. Many future graduates went on to emulate Paul's example and have contributed hundreds of volunteer hours to their fellow citizens.

During the first ten years of my program, a student who was nonverbal, quadriplegic, and had cerebral palsy became a published poet. Another graduate went on to become the founding president of People First of Ontario, an advocacy group for people with developmental disabilities, while several others have gone on to further education, including university. Our program advisory committee is currently chaired by an 80's graduate, who went on to secure a university baccalaureate and is currently working on a Master's Degree. Many other graduates have obtained equally lofty goals in their chosen field. Many continue to stay in touch, and refer new students based on their experience in our program. They bring credit to their alma mater in the workplace and in our community.

### Changing times

I speak of these students above, not only because they were successful, but also because under present ministry funding guidelines and constraints, none of them would any longer qualify for our program. Under current provincial policies, we have been directed to "screen for success" and "success" is defined



almost exclusively as 'competitive employment at minimum wage.' Applicants must come with a "realistic work goal" and a "training plan." Personal supports or attendant care are the responsibility of the student alone. Both are difficult to arrange and prohibitively expensive, thus effectively eliminating those students who require a higher level of daily care in class or the workplace.

To the uninitiated, the complexity of the new application package is daunting and beyond their ability or experience to complete. I have been in this business for 25 years and yet I still had to seek clarification on many items in the new application process so as to help students and their families in filling out the numerous multi-paged forms. In the past, counselors were available to assist applicants, but restructuring within the Ministry of Community and Social Services has resulted in major job cuts and elimination of these once essential services. The handicapped are being directed to bear the brunt of this cost cutting and do much more with much less, learn to live with fewer and fewer supports and be grateful for even the smallest of opportunities. Unlike many of the rest of us, they

have been doing this all their lives to one degree or another, but that doesn't make it right or acceptable.

By now you may be asking yourself, has my dream died? I can assure you it has not!

While on-going funding remains a struggle and my program limps along year by year, the referrals keep coming, the students continue to be successful in spite of the obstacles thrown in their way by their government, and the community rallies to our aid, refusing to accept any notion that the program be discontinued.

### **The dreaming goes on**

Three years ago I dreamt of mentoring new faculty into the field, and that is now in progress. I dreamt of teaching handicapped adults how to search the web and use e-mail and the Internet in their job search. They learned quickly, and now teach me. I dreamt of a time when they would feel confident enough to carry out much of their career research in the community, rather than only from the classroom with support. They are now out and about weekly or more often.

Potential employers call frequently as a result of these contacts and are impressed with our students' initiative and knowledge in their chosen fields of employment. Most employers agree to give the student an immediate work trial and others ask to be contacted at peak times of year.

I dream of a return to the time when success is not solely defined by paid employment, but by other measures equally valid, and perhaps more beneficial.

Twenty years ago, I was told that I was dreaming an impossible dream and not to be too disappointed if my program did not survive after the first year. I just had to understand that the handicapped were an especially difficult group to work with. There was little they could do, and few employers would be interested in hiring them. Fortunately, my students and I refused then, and refuse now, to accept such advice.

And now I continue to dream of the time when all handicapped adults who wish to pursue education, training, work, or volunteering, will be provided with the levels of funding, support, and respect that is so rightfully theirs and that is so wrongfully denied many of them at this dawn of the new century.

My graduates past and future will keep our dream alive. §

## **ComTog On-Line in 2001?**

We shared Jane Green's letter (please see *Readers Write*) with Paul Marshall and Nola Millin secretly hoping that they would be intrigued by the idea of a solely internet magazine. They are cautiously considering a metamorphasized electronic ComTog. Would there be interest in this publication? By potential readers? By potential contributors? Paul and Nola await your reaction.

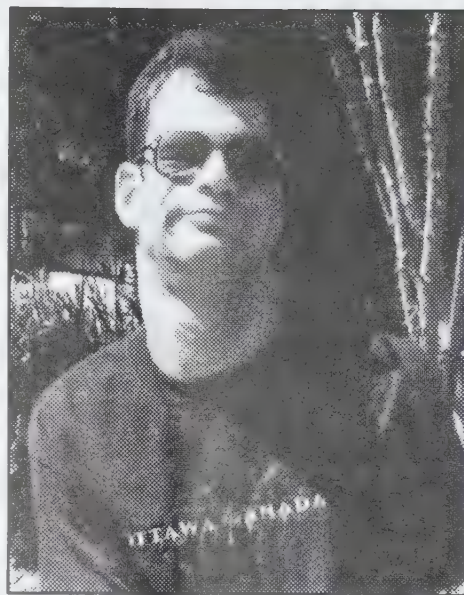
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### As You Help Us

PAUL MARSHALL

*Many of you may not know that Paul Marshall has recently received another honour. The major newspaper in the city where he lives has asked him to do a regular column on disability issues. In this issue, we reprint one of those articles. We are very pleased to have a mainstream journalist on our editorial staff.*



*Paul Marshall*

When our dreams and hopes come into reality, the sun seems to shine brighter and the rainy days are few and far between. Our steps are that much higher, we develop an inner peace and a joy that comes rushing out to meet and welcome the days that are given to us. When positive circumstances are occurring, people and communities reap a harvest of energy that flows and touches an innermost flame.

Last week, I was having lunch with two people who are working in my department at the Bloorview MacMillan Centre for a short term. One is from Sweden and the other from Japan. We somehow got talking about our biggest dreams in life. My friend from Sweden is in his early twenties, and just trying to figure out what he really wants to do with his life. He asked me what my biggest dream was. Out of nowhere, I said "I am living it right now, I am content doing the things in which I am involved already." I

wish you could have seen the shocked look that came over his face by my statement. As I thought about it, I was a little shocked myself. It felt pretty good, however, knowing deep down that I am quite comfortable with my life.

How could I say a thing like that and mean it? After all, I have cerebral palsy, nonverbal at that! I go through my days "fighting" at almost everything I do. I live among people who frequently see my disability before seeing me as a person. So what clicks? Should I spend my life dreaming and hoping of having a "normal" lifestyle without all of the struggles that come with being disabled? I could, and likely everyone would feel I was justified. But the facts are, I will always be a disabled person in this life. I have learned one of life's greatest lessons. I am comfortable with

how the Lord daily shakes and molds my journey. I am convinced that He is the potter and I am just the clay. This is why I personally can travel so far and soar so high. It has nothing to do with being disabled. It is the belief with which I live.

However, I do get depressed and disheartened at the lack of compassion and the absence of a sense of duty of many persons within our society. Too often, silent voices and cries go unnoticed. We are daily swooped away by the big headlines that ignore the real heartbreaks, hidden behind closed doors. Let's crack one of these doors open and take a quick look at a family that is representative of many in our community. You are walking into a home where a mother is trying to care for her disabled daughter. She gets some help on a weekly basis but as you talk with her, you find out that this help is shaky at the best of times. The gray hairs are appearing, the aging process is taking place. You can't help but notice the tired and helpless look. You never would ask, but you wonder what the future holds for this family. At the same time you know there are group homes that take care of persons with severe disabilities. So what's the big deal? Just put her name on a waiting list. Simple, right? Don't worry that there has been no government funding for the building of group homes for over five years and that someone must die before a space becomes available.



I think the greatest benefit of living in countries like Canada and Sweden, is the number of opportunities open to so many of us. That's the *problem* for my friend from Sweden. He, like many in his country and ours, has the privilege of living life with numerous options, having opportunities to move not only in a horizontal direction but also vertical. This means, he can go in whatever direction he wishes and do whatever it takes to realize his dreams. We don't think about it, but this is quite amazing and vital to fostering self-worth. It gives many of us the drive and the happiness to keep growing and reaching out personally and as a community.

The story is quite different for those individuals I know, who are confined to their own homes because of their disabilities. Their minds may be moving faster than yours or mine, but they are

trapped within bodies that their "normal" minds can't control or master. When it comes to activities they wish to join or places where they might like to live, they have very little say and/or control.

Think about this for awhile. You are sitting in a wheelchair looking at those wheels that should be able to propel you where you want to go. But then you look at your shaking hands, whose movements you cannot control. You must go back into your dreams of being able to manipulate a power wheelchair and move independently. This is life, day in and day out, for many persons who are elderly or severely disabled. They can only dream of aspiring to better things be they educational, residential, recreational, or vocational and moving vertically instead of only horizontally. They are confined to moving horizontally, and even

within this direction they experience severe barriers. They must depend on us for the realization of their hopes and dreams for opportunities to move in both directions.

We have to ask ourselves how far we are willing to go as a society to ensure *everybody* has horizontal and vertical directional opportunities in their life so they can reach for their own dreams. What is this article saying to you? Are these words coming off the page and swaying the way you think? Will these words become more than just words? Will they transfer into action? I sincerely hope so. For it is action that makes dreams and hopes come into reality. Here is *my* dream — that we, within each of our communities, will learn to take the necessary action to ensure horizontal and vertical movement opportunities for all.

§

## Communication Matters

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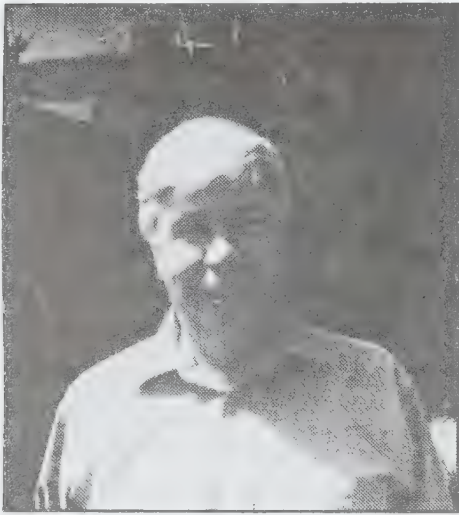
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## Cyberfriends

PETER LINDSAY



*Peter Lindsay*

### Making friends

A dream of most people and a profound need expressed by persons with severe communication difficulties is the dream of having rich and satisfying social interactions with others. One of the essences of being human is interacting with others, of sharing one's experiences and hopes, and yes, one's dreams. Readers of the last issue of **Communicating Together** will recall that making friends beyond one's immediate family and the care givers who are paid to be with you are among the most important needs cited by users of AAC.

This area of social interaction may be one where technology has a good deal to offer. Through telecommunications and access to the internet, people are able to communicate with anyone else in the world who has access to the internet. Moreover, that communication is not compromised from the outset by physical appearance

or speed of response or the need to get to the pub to meet someone.

You can seek friends on the internet in many different ways. There are newsgroups and chat rooms set up to discuss almost any imaginable topic. More and more these internet services are being specifically designed to help people meet others who have common interests. In some programs, you can activate a switch and the program will introduce you to someone else selected at random who is on-line at the same time as you are to see if the two of you want to chat.

But are cyber-friends really friends? Can interacting over the internet where you never actually meet face-to-face really lead to satisfying, long lasting friendships? Judging by the popularity of these interaction services, and the amount of intimate talk that goes on among the people who use them, interacting over the internet can be as intimate or as distant as you choose to make it. It is really up to you and the person you meet. Just like in face-to-face interaction, it can be a meaningless, superficial encounter or it can lead to a very satisfying and fulfilling relationship. You may recall that in a recent issue on sexuality, the feature writer originally met the man she ended up marrying in an internet chat room.

### On being someone else

One of the unique and ultimately profound features of interacting on the internet is that you can be whomever you want to be. Did you not ever dream that you might like to be someone else if just for a little while? Perhaps your dreams would not involve someone specific whom you know but maybe you would perhaps like to be just a little bit better looking, or perhaps a little thinner, or maybe

have a better job? Maybe you dream of living in a big place where there are no mobility barriers and where it never rains.

The new cyber-world of the internet offers the possibility for all of us to have a cyber make-over. Sherry Turkle is perhaps the most prominent and perceptive of the futurists who study the impact of technology on our special lives. In her latest book, *Life on the Screen*, she discusses how her technology students at the Massachusetts Institute of Technology like to take on different personalities while they are on the internet. Many of them spend hours in social interaction building personal worlds where they have all sorts of imaginary possessions, live in imaginary mansions and populate their lives with cyber-friends they meet from all over the world. Their personal websites reflect their new identities complete with pictures of whom they are pretending to be and the places where they are pretending to live. They carry on vigorous and active social lives over the internet through their websites as well as in various associated chat rooms and newsgroups. One student even went so far as to go through a cyber-marriage with a woman from Europe whom he met only on the internet. They invited many of their cyber-friends to the wedding who, in turn, sent imaginary wedding gifts. Everyone at the wedding had met only in cyberspace. As a psychologist, a sociologist and a very astute observer of society, Professor Turkle feels these new opportunities for creating and living out new identities that is emerging with the world-wide-web is revolutionizing the way scientists and people alike think about what is at the core of one's personal identity.



It does not take much imagination to begin thinking of some potentially exciting possibilities for persons who are forced to live a life with very limited mobility and extreme difficulty communicating in face-to-face situations. In principle, these people could build whatever cyber-personality they wish. It could certainly be done but does that make it right to do it? We tend to think that it is cheating to mislead people about who we really are. Those with profound disabilities seem to be forced by circumstances beyond their control to be whom they know they are not. Why is that any more honest than being whom they dream of being in their imaginations if technology will allow them to do so. People are not our disability although others may treat them as if they are. Maybe only something like the internet can provide us with the tools to prove that to others.

### When dreams come true

You may have noted that an important caveat in the above discussion about making friends on the internet is that the person needs to be literate or semi-literate to take advantage of these new opportunities. What about our AAC users who may be literate in a different symbol system such as Blissymbolics or Minspeak or Macaton? Can they also take advantage of the expanded social horizons that the internet provides?

As noted in the editorial for this issue, Blissymbolics Communication International (BCI) has dreamed for a long time about the possibility of building the tools Bliss users need to communicate over the internet. After many years of work, we seem to be on the threshold of seeing that particular dream come true. The case is instructive for illustrating both the joys and the frustrations of trying to fulfill a technology dream.

During much of the nineties, BCI has been working on developing and implemented a program, BlissInternet, that is designed to support Bliss users' access the internet. The overall purpose of the program is to provide the tools that Bliss users need to communicate with one another around the world. The program has three basic components. The first component makes connections to the internet and automatically manages the flow of e-mail back and forth between the internet and the user. The second is a general purpose Bliss message processor that allows the user to create, edit, and print messages in Bliss. This component also includes access to a Bliss dictionary, a translation routine for translating from words into Bliss as well as a set of e-mail commands for addressing, retrieving and reading e-mail messages. The final component that is needed is a program to build on-screen keyboards and set up various scanning routines for the users who is not able to access the keyboard directly. This component is completely independent of the rest of BlissInternet and only has to be able to link to the Bliss processor and the telecommunications component of BlissInternet. For this last component, we used a program called WiViK that became commercially available at the time.

By the 1996 ISAAC convention in Vancouver, Canada, we felt that we had a good working version of the BlissInternet program and were ready to distribute it. Around about that time however, a new version of the Windows operating system was released (Windows 95). This meant that our programmer had to go back to work on BlissInternet to make sure that it was compatible with this new operating system. Unfortunately by the time BlissInternet was working stably with the new operating system, yet another operating system was released — Windows 98! This system was de-

signed to take advantage of the new, more powerful machines that were being released. Furthermore, it was suggested that while we were rewriting it once again for the operating system, we should also upgrade to the latest version of the programming language that was used to write BlissInternet, C++. Otherwise we ran the risk of not ever being able to make improvements in the program. This took another two years to accomplish! Along the way, we negotiated with Handicom to add an e-mail component to their line of Bliss programs. Handicom had already incorporated many of the features in their Bliss for Windows products that we envisioned would be necessary in the next edition of BlissInternet. This led to Handicom adding email to their Bliss for Windows line.

We are finally ready to test Charles K. Bliss's original dream — can the Bliss language really be used to communicate across cultures. He, of course, envisioned its use with scientists and world travellers, not with persons who cannot speak. It is fitting however, that AAC users should be the first group to test the potential of Blissymbolics for world-wide communication. A doctoral student at the University of Toronto, Elizabeth Baird, is currently carrying out a project for her Ph.D thesis in which adult Bliss users in Ontario will be interacting with adult Bliss users in the Netherlands as well as with gifted speaking high school students in Ontario. They will use both BlissInternet and Bliss for Windows to communicate with each other over the internet. One of the major questions to be addressed is whether the Blissymbol system can support communication across cultures and countries using the modern information highway. We hope that it is a dream that will be realized. §

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## Dreaming about Language

BRUCE BAKER

*Bruce Baker is a linguist, the creator of Minspeak and Semantic Compaction and major contributor to the development of powerful AAC systems. We are delighted that he found time to write about his thoughts on language and AAC systems.*

### From Shirley McNaughton

*Here is a companion article to my "Language — More Dimensions Than You Think" Symbol Talk in our Winter 1999-2000 issue. As I explained in that article, Bruce Baker's lecture on language that I heard in Toronto in September, 1999, motivated me to share my thoughts on language as presented earlier that month in Capetown. Bruce agreed to write the following article for **Communicating Together** readers. In doing so, he contributes to a greater understanding of language within AAC intervention, that we both believe is needed. He rightly cautions us to clarify our terminology and to distinguish between natural languages and systematic methods "used to represent or manipulate or communicate information". Interesting reading! I warned Bruce that I would likely add a response to his comments relating to Blissymbols. This follows his article. I know our readers will appreciate the extensive knowledge Bruce brings to this AAC discussion of language.*

Few questions in augmentative communication engender as much passion as the sacredness of the word "language." Is Bliss a language? Minspeak is not a language, because its elements can have more than one meaning! Can a person be a competent communicator without language? Yes!! No!! A lot of heat, but in my opinion, not a lot of light has been shed on this question through the energy of stakeholders in the world of augmentative communication. Well, now you're going to read the correct, full, complete, unabridged answer to important vexing questions about the nature of language. I know the answer is right, because I say so and my closest friends agree with me.

Some of the central questions revolve around the notion of "What is a language?" There is substantial confusion here, because there are several legitimate meanings of the word "language" in common use today. The oldest and first meaning of "language" refers to those communication systems which have arisen in all known human cultures. English, Chinese, Hausa are proper names for these natural communication systems. Technically, these days that usage of language is designated by the term "natural language." There are many properties common to natural language (NL). All of them exhibit polysemy, that is, words have more than one meaning. Second, they are all generative. Third, they all allow for embedding — "I saw the boy whose mother went downtown to buy a coat for him to wear, when it was cold." Natural languages all

exhibit phrase structures. The list goes on.

In linguistics, NLP, refers to natural language processing. No complete understanding of all of the structures of any natural language is known. There are many mappings, but the work is still "in progress." A famous linguistic dictum is "All grammars leak."

The next usage of the word "language" describes almost any systematic method used to represent or manipulate or communicate information. In this group, we find many entries. COBOL, for instance, is a language. C++ is a language. They are computer languages. They are not, however, "natural languages." They do not exhibit polysemy. They do not tolerate much ambiguity at all, another feature where they differ from NLs. They have loads of formal properties to assure direct command structures. They are not natural languages (NLs). Yet we call them languages, legitimately.

Traditional notation systems such as mathematics are in fact, languages using the definition from the preceding paragraph: any systematic method used to represent or manipulate or communicate information. The alphabet is a language. Morse Code, in a famous court case at the end of the 19th century, was designated as a language. Some of these languages have extensive rule systems. Chomsky and Halle have published a deep rule-driven analysis of English spelling which accounts for, in a most detailed fashion, situations often regarded as exceptions. Musical notation is, in fact, a very complex language. It contains all kinds of detail for



situations often regarded as exceptions. Musical notation is, in fact, a very complex language. It contains all kinds of structures that are inherent to it as a representation system and are not a part of the sound processes it represents.

There are other, more colloquial, though legitimate, uses of the word "language," in common parlance throughout the history of English. In the 19th century, flowers were organized into "a language of love." Baby's breath symbolized innocence and purity, while roses symbolized something else. Lovers could read each other's bouquets! Music is said to be "The language of the spheres!" In the phrase, "Watch your language!" — language does not refer to the system but to the particular usage of the system. Examples could be multiplied endlessly. In short, our colloquial use of "language" is extensive, metaphoric, non-technical, and legitimate. In the terms of definitions for the International Society for Augmentative and Alternative Communication, I am sure we need to make at least one major distinction and that is between NLs versus all the others. Bliss is a language. It is a beautiful, systematic representation of information used for communication. It can be extensively manipulated. It is language. However, it is not a NL.

### **Blissymbolics**

Many of the attributes typically found in NL are not found in Bliss. Blissymbolics focuses on its ability to make visible the meaning of a word which in a natural language is completely abstract and not visible. For instance, the Blissymbols for "time" and "all"

are combined to represent the notion usually represented in English by the word "always." Thus Bliss is much clearer than a typical natural language. Bliss does not have as strong a focus on inter-word phrase structure, that is, the structures that occur between and among words. This fact is of great benefit to people who use Blissymbolics as a communication tool. It allows phrase structure to be derived from the NL of the ambient language. Using Bliss in a German-speaking community, for instance, allows reordering action words from the way they are ordered when using Bliss in an English-speaking environment. This also means that people using Blissymbolics to communicate do not need to learn highly abstract grammatical structures.

Blissymbolics is a language in the second sense of the word: a systematic method used to represent or manipulate or communicate information. In a very technical sense, Blissymbolics achieves its systematicity as a semantic combinatoric. Charles Bliss told us, for instance, when composing a new symbol to put the most important idea as the first symbol in the string we were later going to enclose by a cartouche or square. This is a rule of semantic combination. It orders things on the lexical level but not on the phrase structure level.

Thus, Blissymbolics ordering rules for phrase structure do not account for the variety of imbedding processes inherent in natural languages. For this, and a series of other technical reasons, Blissymbolics does not fall into the category of natural language. This is neither to its credit or discredit. In my opinion, some of the reasons that make Blissymbolics not itself a

natural language make it a subtle tool for people to use for people to represent a variety of different natural languages. And, of course, the preceding statement does not, however, mean that Blissymbolics is it not a language at all. It is simply not a natural language. It is an effective teaching tool, a handsome communication tool, and language representation technique which serves many people with disabilities. Nevertheless, it is not an NL. Nor are Minspeak, Picture Communication Symbols (PCS), or Makaton.

### **Minspeak**

Minspeak stands for a family of languages based upon the principles of semantic compaction as implemented by various authors, Tony Jones, (*Language, Learning, and Living*), Bruce Baker and friends (*Unity*), Gail Van Tatenhove, (*Sing to Success*), etc. Minspeak is not a NL, but it is a language in the same sense that Blissymbolics is a language. To reiterate, while being languages, Blissymbolics, Minspeak, Makaton are not languages in the sense that French or German are languages. French and German are NLs! Minspeak has a flexible set of semantic combinatorics which vary from application program to application program. Minspeak allows rapid access to natural languages on computers because of certain attributes of the coding techniques applied to its polysemous icons. Minspeak is not a natural language.

### **Sign Languages**

Sign languages on the other hand are generally considered to be natural languages. Deaf children, from different sign language groups, when mixed together in



Nicaragua, produced first a pidgin and then a creole. The resultant creole invented its own rules which were deliciously complex and not found in any of the pre-existing sign languages they knew. When people who use sign languages have strokes, they lose their ability to generate and interpret signs in much the way speaking people lose the ability to organize or recognize words. PET scans, I believe, have been used to show activation of certain language centers with sign language. Nobody in linguistics that I've ever talked to doubts that elaborate signing systems used by the deaf communities and their families and friends are not languages in the sense of a natural language. They are like French or Spanish, etc. For anyone interested in the status of sign language as a natural language, Steven Pinker's book, *The Language Instinct*, discusses this issue in a series of satisfying paragraphs.

Whether or not a particular language is or is not a natural language is neither a credit or a discredit to its usefulness in any particular context. As the developer of Minspeak, I am not so much interested in the putative status of that system as an NL as I am in its effectiveness and finesse in representing natural language simultaneously to an augmented communicator and his or her computer. Minspeak tries to achieve maximum specificity of output with minimum keystrokes. Whether or not Minspeak is a natural language in and of itself has very little to do with its effectiveness in AAC.

The distinction between natural language (NL) and all the other systematic information representation systems is not well understood

in the AAC community. I believe this has led to the use of the term "language" as a compliment. A representation system is good if it is a language. Something is lacking, if a representation system is not a language. Well, they're all languages, because any representation method with the most modest claims to systematicity is a language, but not necessarily an NL.

I think the field of AAC could be helped if we would focus on the various benefits and weak points Bliss, Minspeak, Makaton, PCS have in relationship to representing natural languages as a whole or a particular natural language. The NL or non-NL status of the foregoing systems is not a useful field of inquiry. Not only do they lack many of the prima facie requirements to be considered a natural language, but any effort to justify to the linguistic community their status as NLs would lead to extremely complex phrase structure, lexical and pragmatics questions bearing little relevance to the utility of any of these techniques to AAC.

### From Shirley again

*Thanks, Bruce, for demonstrating further the many dimensions to language. I am sure many AAC professionals agree wholeheartedly with the need to focus on the features of natural language that are important to the developing child, and from there to examine Blissymbols, Minspeak, Makaton, PCS, etc., as to their capabilities in providing these features. Where I hope we can now move our discussion is to determining the criteria that AAC professionals can use in deciding upon the representation system that best meets the natural lan-*

*guage needs of individual AAC users. Recognizing the "various benefits and weak points" of prominent AAC graphic systems in relationship to "representing natural languages as a whole or a particular natural language" is a worthy goal. As we were going to press, Alan Creak's e-mail message arrived, which presents another interesting dimension to our discussion (see page 23)!*

*A short postscript re Blissymbols. I have often used the language descriptor to emphasize the many language features inherent in Blissymbols. I make no claim for it being a natural language. I do wish to discuss further its syntactic ordering at the sentence level at a future date, however, in order to justify the duality feature I accord to Blissymbols. While it does not provide the variety of imbedding processes inherent in natural languages, Blissymbols does have rules for the combining of words into phrases and sentences. In practice, however, our desire to support the literacy development of Bliss users has led us to follow the model of the natural language for which we are preparing the Bliss user to read and write.*

\*\*\*\*\*

*The plan for our final issue of **Communicating Together** in December 2000 is to devote half of its content to a retrospective and state of the art appraisal of language and literacy in AAC. I invite any of our readers who would like to contribute to these topics to contact me. I hope Bruce or a colleague experienced in Minspeak usage will be one of those sharing ideas in **Communicating Together's** last look at language.*

§



75 Circular Road  
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Dear Shirley and Peter:

I have thoroughly enjoyed **Communicating Together**, particularly in the last years when it seemed to fill a unique placed in the AAC literature in providing a forum for consumers. It was an inspiration to me to hear their voices and those close to them. Hopefully the ground you have prepared will enable those same people to continue contributing and addressing issues. There is a lot to be said to finish something on a strong note which can then be picked up by others.

I would like to share with you something which happened to another publication recently. It

was called "Parenting in the New World Order" and was started by a couple in Ontario to help other parents who were struggling, like themselves, to bring their children up with worthwhile values. As well as containing useful articles, it acted as a forum for readers. Published every two months, over the ten years I subscribed it developed in scope and interest, for example, addressing issues such as marriage relationships and grandparenthood. The mailing list extended farther and farther afield across the world. Then came a letter from the editors saying that they had taken the publication as far as they could, their children had grown up and they had to move on. The ten families who subscribed in St. John's were

going to miss it. However, a young couple in the Caribbean, with the blessing of the previous editors, are now producing a publication with the same name on the internet which can be downloaded free. Some of the original features are missing but it has taken on a life of its own. Not everyone is subscribing here but we can share different topics at parenting meetings. Perhaps something similar could happen to **Communicating Together** with the people whom you have nurtured taking over?

With deep appreciation for all you have both done with **Communicating Together**, and with very best wishes for all future endeavours,

Jane Green

\*\*\*\*\*

Dear Shirley:

In your *SymbolTalk* article in the Winter issue of **Communication Together**, you invited comment on the question of language learning. Here is mine. It comes from a position of interest in communication questions as they affect people with disabilities, but essentially, no real practical experience.

I agree strongly with your views on the importance of language as opposed to preprogrammed phrases. I even had a mildly inspirational article on the topic published in "Closing the Gap" ("Saying something important", issue of April/May, 1998).

On the other hand, the preprogrammed text does provide a comparatively straightforward means of communication for some

people with severe disabilities (I know you know that!), so perhaps one could ask whether there might be ways to greater linguistic competence beginning from there.

It's not a silly question, because in fact once over the first hurdles we do acquire most of our language from sentences we hear or read; unfamiliar words or grammatical structures come to us, and we manage to work out what they mean. There must therefore be ways to acquire language from sentences by a top-down process as well as bottom-up from sememes of various sorts.

I have no idea how to do it, but speculate that it might be possible to provide a sentence-based aid with something like a parser (which need not look like a parser) which could show the sentences

split up into bits in some useful way, so that people could both use the sentences — and any other sentences that might happen to come their way — and get bits out of them to be used to combine with other bits.

That's something like what conventional language-users do. It does give access to language structure more or less as experienced by others; whether it also offers an alternative to the "first hurdles" I can't tell.

I don't know whether anyone has tried that; I do have a vague feeling that I've come across the idea somewhere, but I can't pin it down.

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**Communicating Together** was established in 1982 and has been published quarterly since 1991 by *Sharing to Learn*. Beginning in 1997, it is available both in hard copy and as **ComTog-Online**. The magazine's mandate is to provide a means of sharing the life experiences and communication accomplishments and challenges of augmentative communicators. Its readership includes augmentative communicators, friends, assistants and supporters and all members of the community who wish to know more about those who use augmentative and alternative communication (AAC).

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